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ABSTRACT

This paper discusses new Swedish legislation affecting individuals with disabilities and the social services required under this act. A list of the social services that are available under legislation is provided. The paper also reviews the results of three studies on the effects of the legislation on children (ages 0-21) with intellectual disabilities and physical disabilities. The first investigation interviewed 17 families of children with physical disabilities who had received help under the new act. The second investigation studied the effects of the legislation on 18 children with intellectual disabilities who had personal assistants. The last investigation studied the effects of having personal assistants for children with disabilities in schools in five municipalities. Results found that the number of divorces was much higher in families with children with physical disabilities than those with intellectual disabilities and that women with children with physical disabilities worked outside the home to a lesser extent than women with children with intellectual disabilities. Findings also indicated that personal assistants made the parents feel safe and relieved that their children were receiving good care; however, the school staff sometimes found the personal assistants difficult to deal with because they were outside the school system. (CR)

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The importance of special legislation for people with disabilities, and their families

Dear audience,

My name is Gunilla Andersson-Linder. I'm a social worker in an habilitation-team for disabled children and youth on the island of Gotland, Sweden. Gotland has 57.000 inhabitants., and is situated in the middle of the Baltic sea. At the moment I'm on leave from that work and has an employment as Evaluator at the Department of Welfare Services in Visby.

In Sweden we have a long tradition of special legislation for mentally retarded people. The first Act came in 1944. Then the rights for mentally retarded persons were extended gradually by the Acts of 1954, 1967 and 1984. The last one, LSS (The Act concerning Support and Service for Persons with Certain Functional Impairments) is in force since 1994-01-01. It regulates, among other things, the right to different kinds of family-support.

I have sometimes found it difficult to speak about social services to an international audience. The social systems and traditions differ a lot between countries. Therefore I will start by describing some Swedish phenomena.
In Sweden the Government and the local governments take very big responsibility for the welfare of the citizens. The citizens also generally have a big trust in the public welfare system.
In Sweden most women work outside home, about 80 %. That's almost just as much as the Swedish men do. Because of our fiscal policy its almost impossible for an ordinary family to manage on just one salary. Our children and old parents must therefore be taken care of by public authorities to a large extent.

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There are some important differences between the last act from 940101, LSS, and the former ones. The main-difference is that the group of persons having the right to get help by that law have been extended to include also them with physical and psychical functional impairments, but without intellectual disabilities.
The amount of measures have also been extended from the former Act from 1984. The most important one is the right to get a personal assistant, if your needs for help are very big, or financial support to the costs for such help.

This is a total list of measures for special support and special service, according to LSS:

(Picture 1:)

§9:1 Advice and other personal support
§9:2 Help from personal assistant
§9:3 Escort service
§9:4 Help from a personal contact
§9:5 Relief-service in the home
§9:6 Short stay away from the home
§9:7 Short period of supervision for school-children over the age of 12, outside home
§9:8 Arrangements for living in a family-home or residential arrangements with special service for children and young people who need to live away from their parental home,
§9:9 Residential arrangements with special service for adults or some other specially adapted residential arrangements for adults.
§9:10 Daily activities for people of a working age who have no gainful employment nor are doing a training.

The measure §9:10; Daily activities, is only valid for persons with intellectual disabilities.

LSS is a complementary law. The persons with intellectual disabilities, as well as all citizens, including persons with physical disabilities, have right to get help through the general acts, as The social services act, The national social insurance act and The Health and Medical Services Act. Families with children with physical disabilities had got financial support from the local social insurance office, relief-service inside and outside home from the Social service. The children had the possibility to go to habilitation-camps during the holidays as a form of Medical care. But when these general act are not sufficient for disabled persons, they may now try to get help by the LSS.

The Social Service Act should guarantee all citizens reasonable standard of living, " *--get the support and help they need".* LSS will guarantee disabled persons good conditions of life, they have the right to get special described measures.
The Social Service shall contribute in helping individuals with disabilities to get a meaningful occupation. Individuals with intellectual disabilities have the right to get an occupation according to the LSS. Furthermore you have to pay for help according to The Social Service Act but not for help given through LSS.

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In the year of 1995 I made three investigations in order to study the effects of this new act:, LSS, both for the new group of physically and psychically disabled persons and for those who earlier had had rights according to the former Act for persons with intellectual disabilities:

(Picture 2:)
The investigations

1.) A total investigation on Gotland (n=17), of the effects of LSS for the group of seriously psychically disabled children and youth, (0-20 years old), and their families, who had got some help according to LSS the first 15 months since the Act came into force.
Both parents, teenagers and responsible managers were interviewed .

2.) A total investigation on Gotland (n=18), of the effects of LSS for seriously intellectually disabled children and youth, (0-21 years old) with personal assistants, and their families. I looked specially on the measure Personal assistance, which these children had had even before LSS,
thanks to a local decision.
Both parents, personal assistants and managers were interviewed.

3.) An investigation in five Swedish municipalities of the effects of the measure Personal assistant for disabled children in school.
Both parents, parent-organisations, school-staff and responsible employees in the municipalities, the counties and the local insurance offices were interviewed.

The first and the second investigation can be compared because they both study the situation for equivalent groups regarding size and degree of disability.

The second and the third investigation can be compared out of the fact that they both study the situation for seriously disabled children with personal assistant and their parents.

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From the first two studies I found that the amount of divorces (biological parents not living together) was much higher in the families with physical disabled children than in families with intellectually disabled children, 59% contra 17%. In the second place I found that women with physically disabled children worked outside home at a much lower extent then women with intellectually disabled children. Both groups worked less than the average women with children under the age of 17, according to the Statistical yearbook. The men work just as much, regardless if they had disabled children of any kind or not. The loss of income is to some extent compensated by the governmental care allowance for families with disabled children.

I found some possible explanations to these facts in the investigations. They were found in the different habilitations-measures, family-support (both practical and psychological), leisure-time activities for the children, satisfaction with life-conditions and belief in the future.

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(Picture 3):.
The situation for physically and intellectually disabled children on Gotland, before LSS

	Physically disabled, n=17	Intellectually disabled, n=18	
Divorces, or the like	59%	17%	
Employment, mothers			SY
unemployed	47%	28%	22%
full-time	25%	39%	52%

Habiliation	More medically oriented many operations Training at habilitation-centre	More psycho-socially oriented less operations More training in own environment, (personal assistants)
Family support (practical)	Relief-service in home Short-time families Child-care (0-12 years) Habilitation-camps school- and child-care-assistant	Relief-service in home Short-time families ♦Short-time homes Child care (0-12 years) ♦Prolonged child-care (13-21) ♦Personal contact ♦Integrated and segregated spare-time occupations with escort help Camps. ♦Spare-time consultant Personal assistant in school and child-care ♦Personal assistant in home
Family support staff (psychological)	Team- Team-staff school an child-care staff ♣Special disability-consultants	school an child-care staff ♦(often small classes in special schools) ♦Managers in short-time-homes etc.
Satisfaction with life-conditions	Very heavy and tied up, both physically and psychologically	Not so heavy. Good balance between own parent-responsibilityand relief-help
Belief in the future	Quite dark, specially according education and work for the child More hope for both family and child after LSS. Worry for habiltation for adults.	Quite hopeful for the situation for both child and family Worry for habilitation for adults.

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The results from the second and the third investigations, concerning personal assistants for children both in school and in home, by LSS, point out the great impact of that service for seriously disabled children. The parents felt safe and relieved both practically and psychologically and the children got a good care. Some parents had chosen to be employed as assistant for their child in home. They had sometimes found it too heavy to combine work outside home with the care of the children. This employment gave the family a satisfactory income and a calmer situation.

If the parents were satisfied with this system, the school-staff sometimes found it difficult with the personal assistants in school, because they were outside the school-system. On the other hand they admitted that some seriously disabled children really needed the special help and care which the personal assistants gave. A fact which was supported by responsible staff within the communal administration, the local social insurance offices, social workers in habilitation-teams and parents-organisations.

Conclusion:

Directed legislation, guaranteeing the weakest members of our society special rights and measures, seems, from these studies, to have a great impact on the conditions and qualities of life both for disabled children and youth and for their families. The results may form a hypothesis for more comprehensive, comparing studies in this field.

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